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ABSTRACT

Autobiographical sketches of four Australians living with physical handicaps are presented in this Australian early childhood resource booklet. Life experiences in school and out are reported by a blind man, a young woman who was brain damaged due to injuries in an automobile accident, a mother of a child with spina bifida, and a Doctor of Philosophy in pure mathematics who was born with cerebral palsy. The stories are told in the hope that reading them will provide greater insight concerning how the handicapped can better be helped and in the hope that they educe added respect for the endeavors of the disabled. (Author/RH)

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AUSTRALIAN EARLY CHILDHOOD RESOURCE BOOKLETS

No.3, 1981

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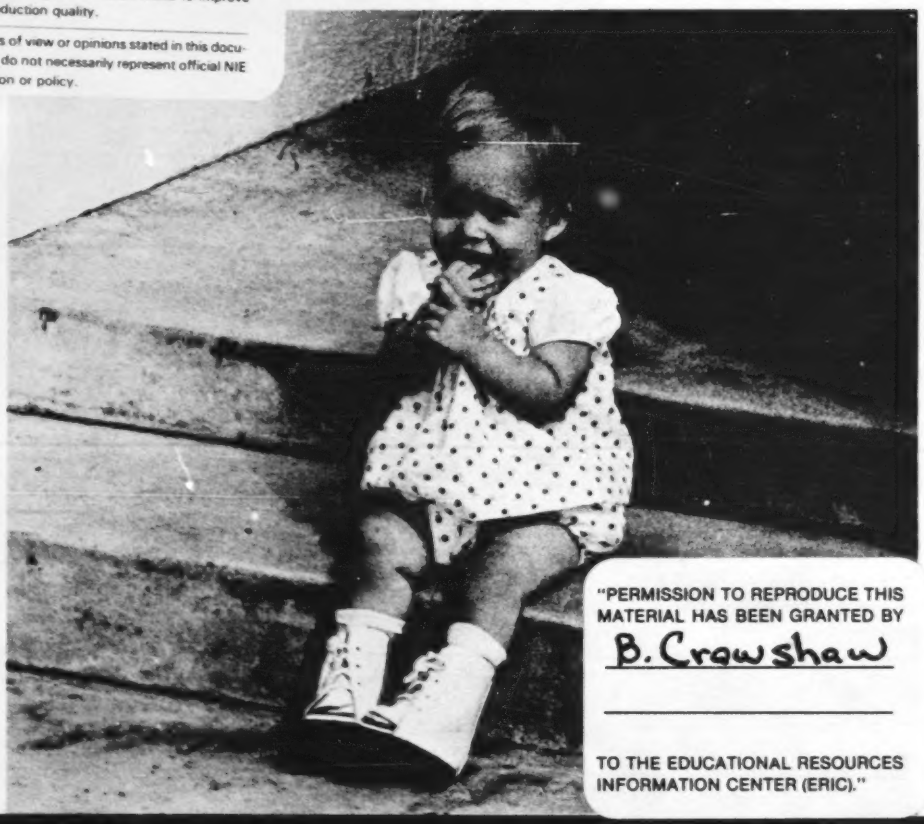
LIVING WITH A HANDICAP



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The purpose of the Australian Early Childhood Resource Booklets is to provide a forum for the publication of Australian information which will be a resource to people interested in young children.

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In this Resource Booklet we have gathered together four people living with physical handicaps who have been generous enough to share with us some of their feelings and experiences, particularly of their younger days.

In this year of IYDP we felt it important to hear from the disabled themselves and to learn what we could from them. We hope that it gives those of you who read this a greater insight into how we can best help them and an added respect for the endeavours of the disabled.

Each in their own words remind us that they are *part* of our society and we should appreciate their struggle to participate fully in it.

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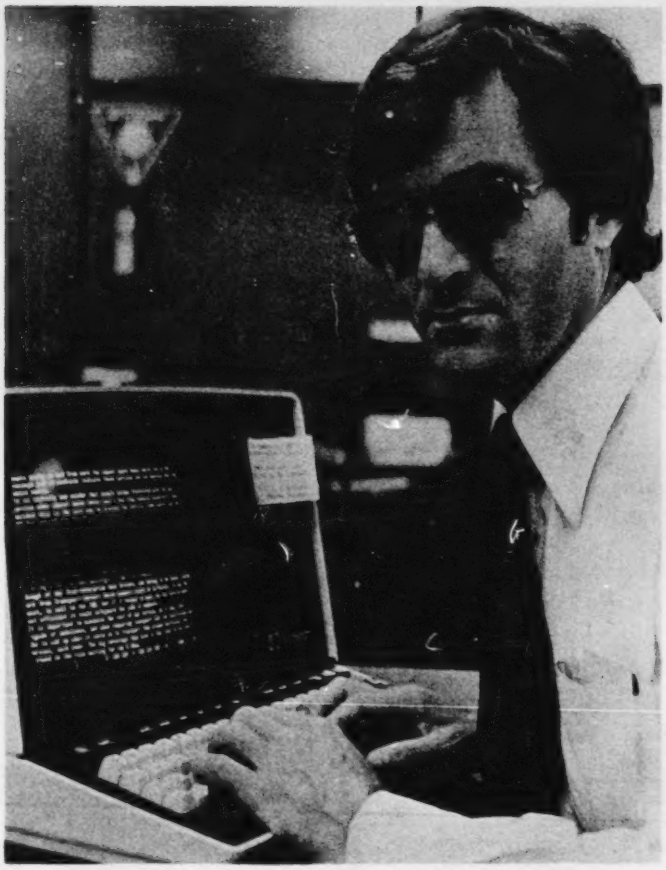


Photograph courtesy Canberra Times

Graham Downie was born in Wellington, NSW, in 1948. He had very little sight though for some years was able to distinguish colours. He grew up on a farm, about 100 kilometres from Wagga Wagga, until going to boarding school in Sydney when he was aged five. The country life was then restricted to school holidays.

One of the ploys used by my teachers to encourage students to work hard at their school work was to say, "You will never do well in the outside world unless you work hard here". I have little doubt that these or similar words have been used by most teachers but I don't believe most teachers would be able to create the same sort of fear of that "outside world" as some of my teachers tried to do.

I attended a school for blind children in Sydney and like many of the students I had limited contact with other children. While this was probably not one of the intentions of the school it was, in my view, the school's greatest negative contribution to the lives of many of its students. It created an artificially small peer group which took away a considerable amount of stimulus and it allowed some children to develop fears about how they may be treated one day by that outside world. The segregation was not very positive either for children outside the school as they could have been forgiven for believing that "normal" people did normal things and those with disabilities did other things.

This mutual lack of knowledge and understanding on both sides has continued for some and continues to cause one of the greatest barriers between some handicapped people and a fulfilling life. One of the justifications for a specialist school for blind children was that they needed specialist teachers and some special equipment. This is still true, but the need for children to develop socially as well as academically has also been recognised by many people and it is pleasing that many children are now having the opportunity to meet other children who once would have been kept apart because of a physical, or intellectual disability.

When my parents sent me to boarding school, when I was aged five, there was little other alternative. About seven years later when I applied all the pressure I could so I might attend the Wagga Wagga High School, my parents were not all that enthused and the staff at the school were apparently even less enthused. My attempt to experience that outside world for myself was postponed for five years. I spent the next five years at the school for blind children, which had become even more intolerable because many of my friends, who had some usable vision, had been accepted into special centres, attached to normal high schools. I ended up with a School Certificate and my parents encouraged me to attend a university. By that state I was so academically unfit that I would not have even succeeded at a Higher School Certificate and as I had no idea about what I wanted to do in life I dismissed the thought of university study.

I considered it extraordinary that I was now being encouraged to attempt study in a considerably more advanced area than I was capable, though I had not been given the chance to leave the special school when I had actually wanted to.

While at school I had been encouraged to believe two things. One was that school days would be the best days of my life. The other was that the outside world was to be feared. Because of my general unhappiness at high school I understood that life had to hold something considerably better than those school days. I had been fortunate to have had enough contact with that outside world to realise that with its hardships it contained some opportunities. I certainly had no intention of working in a sheltered workshop though some of my former school colleagues, some of whom did far better academically than I, are in such institutions.

I will never forget the pleasure of leaving that school for the last time and when thinking back now I seem to recall so many of the things I hated, though there were good times and some good teachers. The teacher whom I recall with the most displeasure, was a chain-smoking woman who taught me that those in authority need not be reasonable or helpful. She was neither. What I recall about her most is that she seemed to object to any person who could not see doing well at any physical activity. To her our only chance of success was to achieve good academic results. My interests were more of a sport and recreation nature and I was never persuaded that recess was a good time to practise Braille reading.

Despite the concern of our teachers for us to do well in the outside world I can recall only one interview with vocational counsellors. I got the impression that the counsellors held out little hope for my future and I recall a group of us later agreeing that the only real purpose our interviews had served was to create a distraction from the normal futile lessons.

My first job, as a process worker in a Sydney factory, was important for at least three reasons. It gave me my first chance to be associated with a large group of people who had had little contact with disabled people. At the same time I had my first opportunity of being associated with many people who had come from

other countries and the job itself was a link in a chain of events which led to better things. One of my strongest memories of the people with whom I worked was that many of them assumed that, because I could not see, therefore I could not hear either. However, there were many people who accepted me as an equal and in return I learned to accept others whom I previously had regarded as unintelligent migrants.

After beginning work on a telephone switchboard in Canberra I believed I had advanced greatly, but after about two years I wanted more. I was getting more satisfaction from activities outside my job than from the job itself. The possibility of further study became a real possibility but this was averted by the offer of a public relations job in Victoria. This job was with the Guide Dogs for the Blind Association of Victoria and I found myself quite unsuited to it. I learned what I should have already known; I did not want to spend my life discussing how I had dealt with blindness. After successfully applying for a job as a journalist with a daily paper I returned to Canberra. After about seven years of searching I had found a position which gave me a sense of achievement. It is a job better than I had ever dared to hope for but a job to which my schooling and previous employment had contributed.

At school I was frustrated when asked by teachers or well-meaning relations, "What do you want to do when you leave school?" At my school I had insufficient exposure to the 'outside world' to know what work was suitable for me. It is likely that this still applies in most schools and I see nothing wrong with young people taking a few years after leaving school to learn more about their world.

With the present recognition of the needs and benefits for disabled people to be integrated into 'normal' schools it should be recognised that there is still a need for specialist schools. Such schools may act as resources for students who attend 'normal' schools. For example, students may attend a specialist school for a relatively short time to learn skills which will enable them to cope within the general school system. The specialist schools may also provide training for specialist teachers before they work in the general system. Visually impaired students may be supplied with material, prepared in Braille, large print or on recordings, supplied by the specialist centres.

The final point I wish to make is one to which I have already alluded. Regardless of what type of school children attend, I believe it is important that they be encouraged to take an active part in community organisations. For me, significant stimulus was gained by my involvement in Scouting, Jaycees and the Guide Dog organisation.

Karen Ferguson lives and studies in Canberra. At the age of five she suffered a car accident which left her with permanent brain damage. Karen is now 24, and through hard work and determination is now studying a Child Care course at T.A.F.E. in the A.C.T.

When I just finished a school excursion I was having a lift with my teacher. The teacher asked me abruptly if I could understand the doctor who had told us how the clinic worked. I was astounded at the incredible question. The teacher thought if I wrote slowly and talked slowly I couldn't understand fast talking. I took a big breath and told her straight off that I wasn't mental, I was physically handicapped. Then I started to tell her why I was physically handicapped and she was astounded that people could survive such a critical accident.

What is it like to be a handicapped person?

Well, a handicapped person has to be strong willed and not give in easily to remarks that someone may make. You have to set a goal and aim at and work to it. Handicapped people are just like normal people, they get restless if they are put in a situation which doesn't fit their normal environment — such as when I was put in a hopsital school where I was the oldest and there were no boys or girls near my own age. Standing in the hall one morning I considered why I was in this shed that was supposed to be a school (it looked like a haystack that had a parking lot for a playground) and I made up my mind right there and then that I was going to work and get out of that situation.

The next day I went down to the hospital physiotherapy room and sat waiting for the therapists to come out of their room but they didn't until five minutes before we were due to go back. This went on week after week. When I asked for help they would tell me to relax. In the hall again, I thought, 'If they're not going to help me I'm just going to have fun till they realise they are put in this situation to help.'

So the next morning I had it in my mind to have fun. It was the therapist's bad luck that it was her first day there. As the head therapist went down the hall the new therapist thought she'd better start work. She had the kind of personality I liked because she plunged right in to what she had to do. She said 'Give me your hand!' (They exercise it and loosen it). I gave her my right hand — my good one. She exercised it and exercised it. After a while I fell into hysterics of laughter but she kept on exercising it. Ten minutes later, the head therapist came back and shouted 'You're doing the wrong hand!'

The most important point I feel is for a handicapped person to have a certain amount of independence and to be accepted by the community as a whole. I have worked to this day to gain that feeling of independence by being able to get around on my bike. I have the feeling of being free — on my own.

Now this brings me to remember the most important time of my life. It was when I learned to ride a two wheeler bike. It was two years after my major car accident and my balance wasn't very good. But seeing the world around me riding bikes and having a great time, I felt envy of the world. So after a long time I thought I would try to ride myself, with my father's help at the beginning. My father bought me a nice two wheeler bike with stripes of red and blue all along the frame. It was a middle height bike with some training wheels. The very next day I wanted to start riding like everyone else, but it took time. My father came home from work early, so he could go and take me riding.

We had to drive to somewhere flat because our house was on a dead end. We drove to a nice park with grass all around so I wouldn't graze myself. I jumped out with excitement of riding like everyone else. My father put me on a seat while he got the bike out. It shone in the sunshine while it stood on the grass. I looked at it — then I looked at some other girls and boys about the same age as me — seven. They didn't have any training wheels so I didn't want any. But my father said 'Try it once with the training wheels.' While my father showed me how to get on the bike I was thinking 'I can ride all over the place and be like anyone else.' Then when I was all set my father gave me a slight push. I peddled with my right foot and hand and I fell to my left. I was too tense, but I looked at the girls riding again and went to get up to try again, but my father thought that was enough for that day.

The next afternoon I thought 'I will do it right this time'. My father came home early again to take me riding. When I sat on the bike I felt very enthusiastic. My father gave me another push but this time I kept my mind on my balance. I was still going to the left while Dad was running on the left side to keep me in the middle.

For the next six weeks my father took me to that park every afternoon until I could ride all by myself. It took a long time but I set out to do what I was heading to do and I made it — with Dad's help. After that I could ride wherever I liked — to see all the world around me, doing the same thing, without training wheels.

On the weekends my father took me up to his parking-lot to ride, in and out of the car lots. One day when the family was walking and I was riding I saw some girls and boys going down the hill without any feet on the pedals. So I went down the same way but tumbled over four times and my father and mother said I only had a scratch on me.

That year I began gymnastics in the YWCA. I looked forward to gymnastics because I could be with girls of the same age and I liked doing the exercises the other girls were doing. We would start by running ten times round the room to

improve our stamina. It was tiring at first. Then we did breathing exercises with touching toes and stretching. After that we would run through some rolling and hand-stand routines which increased our nimbleness and was great for our style of roll. I attended once a week and was very enthusiastic as I was doing something I liked.

In August my school moved to Hartley Street and that's where all my experiences started because after we came back from the holidays there was a new physiotherapist at the centre. I thought she was young and beautiful and she treated me for physio. Everyday when school was out and we were waiting for our taxi to go home, I used to go inside while she was having a cup of tea and ask her if she thought I could make it — could I walk properly? She would say, 'You have the courage, so you will make it.'

After the Christmas holidays I was very keen to get some more information from her but I couldn't find her. I went to the head Therapist and asked her where she was. She said she was in Sydney doing a course. She said 'Why don't you write a letter to her with your left hand?' So I did, and I said: 'I hope you are having a good holiday.' I got a letter back: 'Having what holiday? It's work,' my physiotherapist replied. When she came back she encouraged me some more and picked me up when I wasn't thinking of my walking — which was necessary.

In November we were practising for a gymnastics competition. On the big day we were keeping our spirits up to do the best we could. My performance wasn't up to the standard of the group. I just liked joining in and doing my best. The competition started right on ten o'clock so we all arranged our things and sat down to wait and hear our names called out. The anxiety was great in each of our minds. One girl after another went through the routine with an abundance of liveness and lightness which are very necessary for success. After everyone went through the routine we gathered on the mat with a feeling of satisfaction, which we hoped would put us in first, second or third place. I had my head down with a smile on my face that meant I was glad to be able to perform in a competent style. But you should have seen the smile when I head 'Karen, first place!' My eyes and my smile were nearly popping out.

Entering a club, in particular, brought out the boldness in me to venture into the unknown. In gymnastics I was eager to achieve a handstand because I heard from my gymnast that there isn't any word such as Can't. So I set to work to try and do one. I worked for months on end starting on my head and stretching up to get on my hands, leaning against my mirror. The therapists said it was a waste of time. They said I couldn't do one, but I kept remembering there's no such word as 'can't'. So I kept on trying and it was early in August, while my teacher was overseas, and we had a relief teacher and we started doing handstands. When it was my turn I ran to get the height, then stretched out my arms and went up and all the girls said 'You did it!' It was such a thrill.

The girls you perform with are all for you when you achieve ssomething but the handicapped person has to take the first step. The handicapped person has to learn by experience, but if something goes right with that experience they should not stop there but try and make it better. They should have tolerance and keep on enduring and fighting.

In the year 1976 I decided to join a swimming club to make some more friends and to do the things I like doing best — that is, swimming with people. It was fun but hard work in getting my breathing to function properly over long distance. I remember on one occasion I had been swimming without a break and had just finished fifty metres. When I was two thirds of the way back, my body

began to cramp all over. I was doing freestyle at the time. I knew I couldn't panic because I knew where I would end up — on the bottom. I gradually turned onto my back to float more easily, but I was finding it harder to breathe as time went on so I opened my mouth wide to allow more air in. As I held on, without panicking, someone saved me. It was a little girl who was learning lifesaving at the time and I am very grateful to her.

A year later on the morning of my swimming test for lifesaving I was full of enthusiasm. When I got into the water the first time I sank down in the water but with all my strength I made it to the top and went over to the side.

The first test I had to do was to dive down and pick up a container filled with sand. When it was my turn I swam over to it and when I was about five inches from the container I dived down towards it. I picked it up with my right hand then made my way to the surface and handed it to the teacher.

The next test I had to swim out to my patient and tow her in while her arms were straight and they were holding me by my neck. While she was holding on I did breaststroke back to the side, then I helped her up by pulling her up by her leg.

The last thing I had to do was to swim six laps. The first hundred metres was freestyle, the next hundred metres sidestroke and the last hundred breaststroke. I started at the shallow end, stretched my arms out as if doing the dive roll, then pushed off with my feet. I glided on the water, then I started my arm movements, taking a breath each third arm movement. When I finally reached the other end, I was out of breath. I thought I would go slowly back because I thought 'It doesn't matter how long it takes as long as you try your hardest.' that's what I did. I turned to go back and started with my left arm through the water. I was out of breath after two strokes but it didn't occur to me what the trouble was, so I went on through the water. I was losing my breath quicker as time went by, but I couldn't understand why this was happening. I just knew I had to do my best. Then it happened, while my breath was out and I needed a refill I was ready to lift my head for air when I discovered I didn't have control of my muscles. I was frantic to get some air, with uncontrollable arms thrashing the water, and after about the fifth gulp of air I heard someone say 'Karen' and she pulled me to the side.

All through my third year at Hawker College we were cycling everywhere to get in shape for our trip to Victoria which was going to be at the end of the year. I finally joined in a ride to Murray's Corner, camping the night and riding on until we got to Point Hut Crossing where the teacher thought I had had enough, so my Mum picked me up.

Another long ride was back from Blue Range Hut to Cook. This was good experience in releasing that pent up energy which is building up in you and in releasing it while you're seeing the world. You think life is wonderful when you can see kangaroos roaming around and rabbits munching at the grass while the sulphur crested cockatoos fly above keeping an eye on the ground below.

A week before the trip to Victoria we were invited to ride up Mount Franklin with Pedal Power. We met at the corner of the Cotter on a Saturday to start our ride up the unsealed road. While your legs are going around all the time they get weary but just when you are about to give in, your stamina grows to get you up the steeper parts of the mountain. That's how my body regained the energy it needed to be the first girl up the mountain out of five girls.

It took eight hours to reach the top of Mount Franklin, minus two hours we had for lunch while waiting for the others. The barn where we stayed was made of wood and up the stairs in the room above were wooden double-decker bunks,

two on each side. In the kitchen there were the essentials to make a staple meal. After dinner that night we all tracked up the mountain to some rocky outcrops and looked across the valley and there, shining in the distance was Canberra with its lights twinkling. It was a sight to be seen. After we took ten deep breaths of the clean air we felt relaxed.

Our trip to Victoria was a breeze after Mount Franklin. On a Tuesday we drove to Victoria with our bikes stacked up on the bus. When we stopped at Beechworth it was dark but we managed to get our tents up so we could sleep and get ready for the long ride ahead of us. The next morning we set out on the long ride to Bright, stopping at Yackandandah overnight. It was flat all the way. Yackandandah was nice and interesting with some caves which were astounding. On arriving at Bright I found it quiet with a character of its own. The river Ovens runs its course downstream with eucalypts lining its banks. We put on our swimmers and had a nice refreshing dip.

Early next morning we started out on the ride back to Beechworth. We were warned that there was a gigantic hill just before you reach Beechworth and it got me thinking. I was thinking that I would have to get off and walk up it. When I was riding along the quiet country roads I stopped to have a chat with a farmer's wife who was getting her milk. She asked me where we had ridden from and where we were heading. She told me what we had ahead of us. My imagination started to grow. I thought it was a never ending hill and I was looking out for it. At a little hill a teacher got off his bike and took some photos. I thought that was strange but I didn't take much notice as I was thinking of the daunting experience of a hill that was still to come. When we stopped to have lunch I heard the teacher talking about the hill. I said "What hill?" I didn't know that where the teacher took the photograph was the steep hill. I was amazed.

SOME FEELINGS

It is important to have the self-assurance to learn to speak firmly to the average person when they feel embarrassed and try to explain why you are how you are. I was glad that I could explain to the teacher that I could understand what was said. That was what started me on explaining to others what it feels like to be me.

Being in a family with other children, I think that younger members find it difficult to understand the problem of a handicapped person and the need for the extra time and attention spent on her. But, if there is love in the family everything turns out in the long run.

Rosalynd is the mother of Rebecca who is a spina bifida child. She also has another little girl fourteen months younger than Rebecca. Rebecca is now in first class at her local school. Rosalynd shares with us some of her experiences of what it means to be the mother of a disabled child. Rebecca is a laughing child, and a very brave one, and endears herself to all who meet her.

We had waited excitedly for 36 weeks for the arrival of our first baby, so that it was with disbelief and horror that we received the news that our precious baby was a "spina bifida". Like so many people, we had never even heard of the term before, let alone knew about its terrible consequences. Our situation is a little different perhaps, in that our daughter was born while we were living in South East Asia. Rebecca was born at a small hospital, the doctor a personal friend with only slight knowledge of spina bifida and its management, and it was ultimately some weeks before we could find an adequate explanation of what spina bifida actually is.

After much searching of libraries and correspondence we came up with the definition of spina bifida as a congenital malformation of the spinal cord, of the immediate coverings of the cord and of the backbone which normally encloses and protects these structures. This results in a swelling in the midline of the back which is usually covered only by a thin membrane and not by skin. The swelling contains cerbro spinal fluid. The nerves of the spinal cord are thus very vulnerable and there is often partial or complete paralysis below the level of the defect. This may affect not only the limbs but also the bladder and the bowel, resulting in incontinence.

In Australia, 1 in every 1,000 births involves some degree of spina bifida. In many cases, hydrocephalus also occurs where the spinal fluid which is normally formed near the centre of the brain is unable to get to the surface because the narrow channels are blocked. Pressure builds up and the child requires a shunt or special valve placed in one of the cavities in the brain to artifically drain the excess spinal fluid through the shunt and then through tubing into the heart or peritoneal cavity.

A couple of days after Rebecca's birth, we learned from a Singapore neurosurgeon that Rebecca had all these problems and more, and that her prognosis was very poor. After much soul searching we decided that there was little to be gained by returning to Australia with her and set about trying to bring some order back into our lives. We were in a terrible limbo — one moment praying that she might live and in the next moment hoping that she wouldn't. Some babies are remarkable in that despite all odds they will not give in and after three months of hospitalization, ghastly investigations and still a poor prognosis, the medical authorities decided there was nothing more that they could do for her in Singapore, and that we should take her back to Malaysia.

All along we'd thought that losing her wouldn't be quite so hard if we had never taken her out of hospital, so that it is impossible to describe the flight home. We'd not even been able to hold her in our arms because her lesion was so large and difficult to close, and here we were flying back home, having to learn how to look after her, with the added problem that spinal fluid was still oozing out of the lesion on her back. Life seemed to consist of dressings. Her lesion is very low and being so hopelessly incontinent, she'd be continually damp and we'd no sooner get a quite complicated dressing on than it would be in a mess again.

How we kept our sanity during those early days is a mystery, but Rebecca continued to grow stronger, required more and more hospitalization and investigations, so that it was with considerable relief that we returned to Australia when she was 2½ years old and experienced the luxury of the Spina Bifida Clinic at the Royal Alexandra Hospital in Sydney, with a team of dedicated people to look after us, and finding other parents in Australia who had been through much the same experiences as we had.

I remember reading somewhere where a spina bifida family is a handicapped family — life consists of bladder infections, shunt infections, shunt blockages, shunt revisions and endless surgery for one thing or another, usually followed by months of plaster during which you desperately pray that the surgery is a success, and of course constant separations of family members during hospitalization. It is not surprising then that one hears that spina bifida usually makes or breaks a marriage and one is eternally grateful for a loving and supportive partner.

In the back of our minds from very early on was always the terrible prospect of how Rebecca would ever cope with school if she reached school age. Even the idea of pre-school can be a nightmare to parents of handicapped children as it was with us. I started in late 1977 by phoning different pre-schools in the area where we then lived. Having to explain to the teacher what spina bifida is, and also explain that Rebecca was in calipers but that her legs were so spindly she couldn't walk in them, weren't conducive to having her accepted into a normal pre-school. Then we located a wonderful woman running a pre-school about 25 minutes drive from where we lived. Yes! She knew about spina bifida and she'd be absolutely delighted to have Rebecca. There followed 12 months of wonderful learning activity and miracles — Rebecca started to take her first faltering steps

without all her appliances. We then moved to Canberra where our local pre-school accepted her without hesitation.

Wheelchairs and orthopaedic appliances are bewildering and clumsy looking (even to parents at times) but usually not so to the child. Although Rebecca was mobile and did not wear any appliances when she started pre-school in Canberra, she did have major orthopaedic surgery requiring plastering from toes to hips for 2 months. The surgeon usually plasters the child in such a way that she can still roll around the floor without doing any damage to the surgical work. Rebecca was small enough to fit into a lightweight collapsible stroller, and the pre-school staff were more than happy to wheel her from room to room.

When enrolment time arrived for primary school we decided to boldly approach our local school. Rebecca was reasonably mobile by this time, although she couldn't manage steps other than on 'all fours' but this didn't worry her. Primary school leads me to the problem of incontinence — this together with the child's degree of mobility seems to be the deciding factor as to whether a normal school will accept a spina bifida child. By the age of five years most spina bifida families are managing the problem of incontinence quite well. Personally, I can see no reason whatsoever for a spina bifida child being prevented from attending a normal school because of incontinence. Usually mothers are more than willing to be 'on call' in the case of an accident and despite our daughter being hopelessly incontinent and my hanging on the end of a phone, the school did not have to call me once during 1980. Accidents do happen (even to continent children).

The management of incontinence requires considerable experimentation. Most parents cope quite well with the problem and do not expect teaching staff to be involved. If the child is having problems I hope that the teacher will bear in mind that the parent is usually trying to sort out the problem. Most parents are aware that good management of incontinence means social acceptability and self-confidence, and poor management results in the opposite. We cope with urinary incontinence by 3 hourly catheterisation. This originally involved my wearing a path between our house and the school until I happened upon our 20th century 'Florence Nightingales' — the Canberra District Nursing Service, attached to the Health Centres. They call at the school on four days a week to catheterise Rebecca for me and of course I find the freedom impossible to describe, after being so tied down.

Most mothers would do anything to have their spina bifida child integrated into a normal school, but of course this generally results in a mammoth effort on the part of the mother, and we all have our physical limitations. Which leads me to suggestions for handling Mums of the handicapped! I always hope teachers will make allowances for a mother when she seems to be making a mountain out of a molehill. Bear in mind that the spina bifida family are under continual pressure which can be made worse where the child has an uncertain or poor prognosis. Many parents travel interstate for treatment involving long hours of travel and a very tired mother, so that it is quite easy to get over-dramatic about a problem; but then life with a spina bifida child can be full of drama.

Independence appears to be a very personal thing varying from family to family, but from personal experience I would say that on the whole, spina bifida children are fiercely independent. People often with the best of intentions and the kindest of motives, tend to think of the handicap or disability first and the child second, instead of the child as a child who happens to have a disability. Pity for the disability seems to override appreciation for ability.

When meeting Rebecca's teacher for the first time I very boldly insisted that she treat Rebecca just as she would all her other children, all along desperately hoping she would come to Rebecca's rescue if she couldn't cope with a situation. Rebecca is now in her second year of school and to all appearances can handle any situation but only, I think, because she had the good fortune to have a guardian angel in her first teacher, who managed to surreptitiously extricate her from impossible situations so beautifully that it was never obvious to Rebecca, and who also helped instil the confidence that is so obviously difficult for the disabled child to achieve.

How does Rebecca see herself? We tend to swing from her being full of confidence in her appearance to asking in that quiet moment before she goes to sleep 'Mum, why was I born all broken?' We often have a discussion time over the dinner table when Rebecca and her sister will be discussing their day at school. Recently her sister said her teacher had told her that 'God made her'. Rebecca immediately replied that 'God couldn't have made her as he wouldn't have made such awful mistakes'. This perhaps is the hardest aspect of dealing with one's child's disability. We seem to be continually working at building up confidnece in her image and letting her know just how terribly much she's loved, and we like to remind her that she is the only girl in her class to be invited to every birthday party.

Sporting activities for spina bifida children are very limited, however most do well at swimming and horseriding. Where the child is attending a normal school, rather than have the child sit on the sidelines, I can't see that it would cause any disruption to have the child pursue their own sporting activities. Rebecca at six years of age has become quite an accomplished horsewoman and her school did not object to my taking her to her riding lessons when she could not participate in school sports.

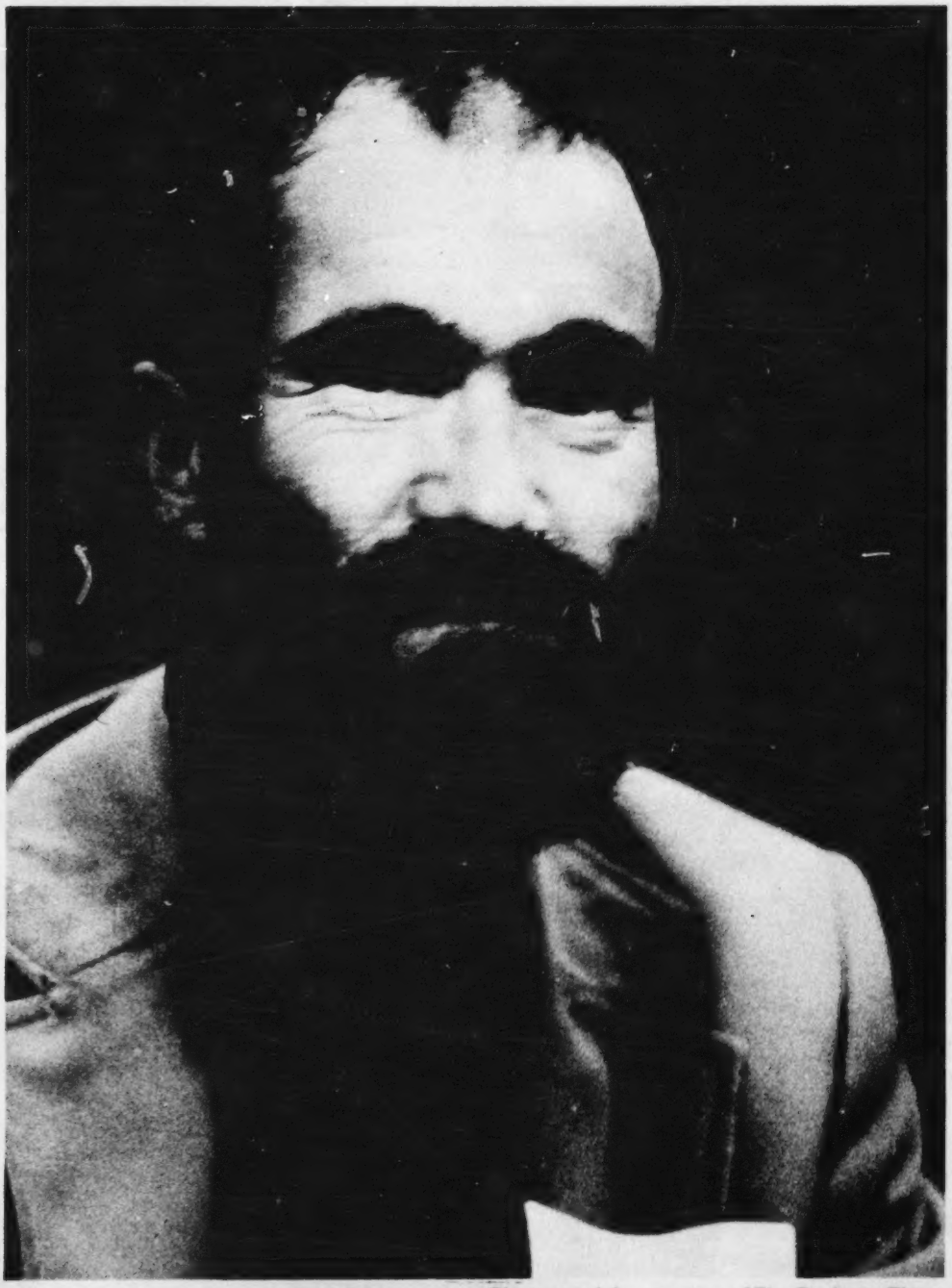
Many spina bifida children have no intellectual disability, but can have a mild to moderate problem with fine motor co-ordination. This really becomes apparent in their first year at school, although most will be having occupational therapy sessions along with physiotherapy, and I would suggest that it takes very little effort on the part of the teacher to liase with the child's occupational therapist, and one or two sessions of occupational therapy each week is sufficient for the child to keep up with the rest of the class.

Something that really concerns me and is just as important as the management and acceptance of the disabled child, is the acknowledgement of siblings by the spina bifida child's pre-school and primary school teachers. Especially in Canberra where one might not be so fortunate in having grandparents to take over during hospital trips, the siblings' life often consists of being shunted from one kind family to another. Generally they are forced to grow up very quickly and are so rarely the centre of attention when the disabled child is around.

For anyone not familiar with the spina bifida child, integration into normal society and the normal school system must seem to be an insurmountable task, but it is only by giving the child the chance to cope that he or she can become a well adjusted and independent person.

Remember, given the chance, he or she will cope well with his/her disability from a very, very early age. The spina bifida child is usually fiercely independent, so must be given the chance to integrate into a normal pre-school and/or primary school at the very earliest opportunity.

Dr John Hickman lives and works in Canberra, and has generously consented to tell us about himself and his school days. He has recently won a 1982 Churchill Fellowship to study in Britain, the United States and Sweden, programmes for the the rehabilitation of the disabled.



Photograph by courtesy of The Canberra Times.

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CHINA ASHTRAYS AND CRICKET BALLS

I was born with cerebral palsy, a brain-damage disability which in my case causes certain muscles to be permanently in a semi-contracted state, and also causes irregular, involuntary movements of the various limbs. Owing to the first condition I am required to use a wheel chair for all but the shortest distances, whilst the second condition means that I cannot perform such mundane activities as holding a pen or lifting a glass of water. All my written work is done on an electric typewriter which I operate by tapping the keys with a stick; whilst a short time ago at an official ceremony at Yarralumla I probably set some sort of precedent by drinking champagne out of a beer glass through a plastic drinking straw.

I was born in Adelaide in November 1943, and in March 1946 started attending a special school for physically handicapped children. I remained at this school, Ashford House, until the end of 1962, by which time I had matriculated and had gained entry to Adelaide University. There I obtained an Honours Arts degree, majoring in mathematics, after which I transferred to Flinders University, subsequently securing the degrees of Master of Science and Doctor of Philosophy, both in pure mathematics. Upon completion of my doctorate I was offered a research post at the Australian National University.

My first three years in Canberra were spent on campus at Bruce Hall: then I decided to try living by myself and moved to a small flat in Queanbeyan. During my twelve months in Queanbeyan I learnt the basic domestic skills involved in living alone, after which I moved to a larger home unit in Hawker, where I was able to pursue my independence a little further. The shift to my present home in Melba occurred four years ago. I have tried to put down some of the experiences of pursuing an independent lifestyle in a book that was published in April last year.

I have been asked to describe a couple of childhood experiences. If these seem "ordinary", then that is because physically handicapped children are "ordinary" children some of whose actions just happen to be limited by a physical disability. They do not (in general) want to be treated as "special" people, except in those areas specifically affected by their disabilities.

And why should they be?

School plays a major role in any youngster's life; with a handicapped child, the curriculum is complicated by the necessary intrusion of physiotherapy, speech therapy, and for the younger children rest periods, during the normal school day. These extra activities naturally restrict the amount of formal schooling that can be imbibed in one day; and this fact, when combined with the communication difficulties that beset a fair percentage of handicapped children, means that quite often the disabled child spends one or two more years at school than does his nonhandicapped counterpart.

In addition to the extra-curricula activities mentioned above, every student at the school I attended, Ashford House School in Adelaide, spent one afternoon a week at handcraft lessons run by the Red Cross. Each student could choose a topic, ranging from pottery through leather work and basketry to weaving. At the end-of-year prize-giving the student was presented with the items completed during that year.

It might seem that for someone whose hand disabilities are sufficiently severe to prevent him from holding a pencil or from picking up a glass of water, an attempt at any of the above-mentioned projects is just asking for trouble.

Youthful self-confidence recognizes no bounds however, and I announced my intention of taking up pottery. Specifically, and for no reason that I can now recall, I wished to make an ornamental, miniature table in the Queen Anne style. Our handcraft teacher, after she had overcome her initial shock, set about the task in her usual calm manner.

Somehow things did not quite work out as planned. The three delicate legs I had envisaged contrived by some obscure means to entwine themselves into one thickened J-shaped stalk; moreover the tabletop, far from being flat, actually possessed a curvature whose complexities would frustrate even the most avid differential geometer. After some experimentation my mother found a flat area of the top, whose dimensions were sufficiently large to provide the thing with some degree of stability (provided that one did not talk above a whisper in its presence), and for some years it gave useful service as a highly original ashtray.

Pottery then was clearly not my niche. Basketry was a little more successful, but had the drawback that with me on one end of a length of cane, anyone within reach was automatically in danger of losing an eye.

And so I arrived at my true love — weaving. passing a shuttle through the two hundred or so threats that constitute a weft may not seem the sort of task at which I would shine; nor was it, if I adopted the traditional, gentlemanly approach to the job. However, I discovered that by taking good aim and shying the shuttle in the general direction of the weft, I had a better-than-ever chance of getting it through without mishap. People just had to learn not to stand on the other side.

The novelty of straight two-shaft weaving soon wore off, but the fascination of four-shaft weaving and its potential for the creation of complex woven patterns (particularly if more than one warp thread is used) remained, and for some years I was perfectly happy weaving mats, scarves, stoles, etc. After my formal handcraft lessons finished at school, I purchased a secondhand fourshaft loom and kept up my weaving at home for a time.

In a school catering for physically handicapped children of all types, ages and characteristics, the unusual or unexpected was not confined to the handcraft room. Nor was it always confined to student activities.

Ashford House was situated on Anzac Highway, one of the arterial roads connecting the inner metropolitan area of Adelaide with the western suburbs, and even in the '50s and '60s peak hour traffic along the Highway could be very formidable. In its early years Ashford House possessed a half-acre block of land adjoining the school grounds: later on this block was used to site an extension of the school, but at first it was used to maintain a variety of school pets. Officially these animals were used in Nature Study classes — in practice they were just pets. Included amongst these pets were three sheep.

Now sheep are by tradition docile creatures, quite content to graze quietly in their own territory and to let the rest of the stupid world rush madly by. Our sheep, as was only right and proper for upstanding Ashford House members, were different. When one of them discovered, one afternoon following the departure of the school buses, that the front gate had been left unlatched, there was no hesitation; all three stepped forth eagerly to sample the joys of 5 o'clock traffic.

The remaining Ashford House staff, although being very experienced and competent in the handling of disabled children were not quite so practiced in the fundamentals of stock and station management, and the late afternoon traffic of the inner south-western suburbs of Adelaide came to a standstill whilst staff and

sheep frolicked merrily up and down Anzac Highway, serenaded by periodic cries of "Here sheep! Nice sheep!"

Despite the so-called extra-curricular activities in which the handicapped child must participate, I feel that education must be given priority wherever possible; for if a physically handicapped person is to achieve any real form of independent lifestyle, then he must compensate for his inferior physical skills by trying to maximize his intellectual skills. This was the philosophy adopted at Ashford House; and if results taken on a per capita basis constitute any sort of criterion, then this philosophy must surely be rated a success. From the six of us who started secondary school together, one of us is a Justice of the Peace and is in charge of a rehabilitation service in Adelaide, another has obtained a doctorate in pure mathematics, and yet another is a radio engineer and runs his own amplification business.

It is of course useless to have this realistic approach to physical disabilities adopted at school unless a similar approach is adopted at home. The physically disabled child needs to participate in games, in family activities, and in family decision-making in exactly the same way as he would do were he not handicapped. Clearly you do not ask a child with a severe hand disability to wash up an ultra-sharp carving knife or a unique crystal decanter; your concern is in the first case for the safety of the child, and in the second for the safety of the decanter. In situations like these it is a mistake to underestimate the appreciation that the child has for the current state of affairs; a handicapped child knows what tasks are beyond his capabilities, and will not normally ask to be allowed to undertake one of these.

My own life at home was most fortunate in this respect; and this had an overwhelming beneficial effect on my gradually developing self-confidence to cope with the problems of everyday life.

Cricket used to be one of my abiding pastimes, and it was therefore quite an event when one year my brother Robert and I were given a genuine cricket ball as a Christmas present. Immediately all tennis balls were banished to the back of the cupboard, and the long-suffering tennis court in our back garden had once more to undergo the trauma of being turned into a miniature cricket ground.

My father eyed these preparations with some misgiving, having in mind the relative proximity of the bedroom window of the separate flat occupied by my great-aunt. To be sure, this was the one window within "striking distance", and its demise could only be achieved by a cover drive far more accurate than those in the repertoire of either Robert or myself. Nevertheless, flukes occasionally happen, and so Dad decreed that prior to starting the game, we should receive some instruction in the art of playing the ball down.

Taking over the bat from me, he invited Rob to send down a delivery with the brand new ball. Rob responded with a nice, gentle ball just outside the off stump, and Dad, in the heat of the moment, forgot his assumed role of instructor and let out with a beautifully executed cover drive — the ball fairly flew through the air. Fortunately my great-aunt was not home at the time. The window was quietly replaced as soon as possible, and the subject of cricket was dropped from the dinner conversation for the next week or so.

In May of 1958 an interstate camp for physically handicapped boys between the ages of 12 and 16 was held at the Victorian township of Yarra Junction. Victoria as host had six representatives; each other state was invited to send two — one from the country area and one from the state capital. All states except Queensland responded, and I was chosen as the Adelaide representative. Initially

there was some trouble with my proposed trip to Melbourne; the airline with which my flight had been booked, when it discovered that I was physically handicapped, refused to accept me as a passenger unless arrangements were made to have a "supervisor" accompany me during the flight. The problem was speedily resolved by switching my flight to the other airline, which raised no objections at all.

The organization and running of the camp was truly splendid, and I have always felt it a pity that (as far as I know) the other states in succeeding years did not follow Victoria's lead. Almost every day throughout the duration of the camp short tours were made to points of interest — these included visits to Port Melbourne, parliament House, the Healesville Sanctuary and a fascinating guided tour of a large paper mill. The tours were organized with as much care and attention to detail as was the camp itself; at no point can I remember any delays being caused through lack of ramps or other access problems.

One of the staff brought along his dog, a kelpie cross named "Bill". Bill and I took an immediate liking to each other, but it was rather disconcerting for me to discover that Bill did not consider this affection to be concluded at "Lights Out", but would every night take over the bottom quarter of my bed as his sleeping area. Had this area remained at 25%, then everything would have been lovely; but Bill was a rather large kelpie cross (or so he seeemed to me), whilst I at 14 was rather small. As the night wore on, Bill would periodically stretch, at which time I would have no alternative but to contract. By morning the situation of the previous evening would have reversed itself, with Bill occupying the bottom three-quarters of the bed and me tucked up in the remaining quarter.

The main recreational pursuits inside the camp were chess and table tennis. I had taught myself the fundamentals of chess just a few weeks earlier, and whilst I could beat Alan, one of the Tasmanian representatives, I was no match for Colin, who came from Geraldton. By far the two best table tennis players in the camp were Bob and Tony, from Melbourne and Sydney respectively. After they grew tired of pitting their skills against each other, they went in search of the most gullible person in camp (me), to browbeat him into learning the rules of their precious game. However, Bob insisted that I should be taught the Victorian rules, and Tony was equally adamant that I should learn the NSW version.

After becoming thoroughly bemused by these different versions, I took the only proper course open to me and appointed myself camp umpire.

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